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ABSTRACT

This fact sheet uses a question-and-answer format to summarize information on estate planning and trusts for parents of a child with mental retardation. Questions and answers address the following topics: the importance of careful financial planning for someone with mental retardation; how inheritances affect the child's eligibility for Medicaid-funded services and Supplemental Security Income (SSI); use of a trust to ensure a son or daughter's financial security without jeopardizing the individual's SSI and related benefits; types of trusts that are commonly used for this type of planning; the "master cooperative trust"; the process of setting up a trust (testamentary and inter vivos); and new legislation allowing preservation of a child's eligibility for SSI or Medicaid if the child has already received an inheritance. (DB)

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Q&A

# Future Planning: Making Financial Arrangements with a Trust

by Rick Berkobien & Theresa Varnet

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Q&A

# Future Planning: Making Financial Arrangements with a Trust

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## Why is careful financial planning important for someone with mental retardation?

Our current service delivery system often requires that individuals who receive publicly funded mental retardation services be poor in order to receive funded services. Usually people with mental retardation receiving services, such as those paid for by Medicaid, must contribute toward the cost of their care with the proceeds from their earnings, Supplemental Security Income (SSI) or Social Security Disability Insurance checks. They are then left with only a small personal care allowance (as low as $30 in many states) to cover the cost of clothing, toiletries and related items. Parents often subsidize the costs of these items because the personal care allowance is insufficient.

If a parent dies and leaves their son or daughter an inheritance to help cover these personal costs, the inheritance will be considered an asset and the individual receiving the inheritance will be charged "cost-of-care." Publicly funded residential costs can be expensive, sometimes amounting to several thousand dollars per month. So, having to pay even some of these costs can quickly deplete funds needed for other purposes.

Careful financial planning enables a parent to provide help in purchasing personal care needs after the parent dies without exposing their son or daughter to cost-of-care charges. The local or state mental retardation services agency can provide information about how that state handles cost-of-care issues.

## If my child is receiving Medicaid-funded services, won't he or she continue to receive Supplemental Security Income?

Many individuals with mental retardation receive SSI, a monthly monetary allowance that usually makes the person eligible for Medicaid health benefits. Adults are eligible for SSI if they have a disability that prevents them from working and earning a self-sufficient wage, and they do not have more than a certain amount of assets. Children also are eligible for SSI if they have "marked and severe functional limitations" from a physical or mental condition.

Medicaid often pays the cost of certain services for people with mental retardation. In order to remain eligible for Medicaid, a person cannot have more than $2,000 in cash assets or assets which can be converted to cash. In some cases items such as a home, car or a burial plot may not count as available assets.

If an SSI/Medicaid recipient has access to more than $2,000 in available assets, he or she would lose eligibility for SSI and Medicaid. An inheritance or gift above that amount would, therefore, generally disqualify a person from receiving SSI and Medicaid. The recipient would have to spend down the amount to below $2,000 before he or she could reapply for SSI or Medicaid. The inheritance or gift will not have benefited the recipient if the result is the loss of SSI and Medicaid.

## How can I ensure financial security and not jeopardize my family member's benefits?

There are ways that parents can help ensure a degree of financial security for a son or daughter with mental retardation without jeopardizing the individual's SSI and related benefits. Some parents have chosen to disinherit the child with mental retardation and leave another sibling an additional share with the hope the non-disabled sibling will use the money to benefit the sibling with a disability. This is sometimes referred to as a "morally obligated" gift. Unfortunately, the assets often intended to benefit the child with mental retardation may not be spent on this person, and if the non-disabled sibling is divorced or dies prematurely, the extra funds may be distributed to a divorced or widowed spouse or another heir.

A more reliable method of providing for financial security without jeopardizing government benefits is through the use of a trust. Trusts hold money or property that the grantor (the person who sets up the trust) leaves for the beneficiary's economic benefit. Unlike an outright gift or inheritance through a will, trusts usually contain carefully written instructions on when and how to use the trust's contents.

Parents or others can set up a trust while they are alive or as part of a will. If parents set up a trust while still alive, they can be the trustee (the person who manages the trust). They can also assign someone else to be trustee. A trustee can be a person or a financial institution.

A trust may be designed to distribute assets to one or more beneficiaries at certain times or under certain conditions. Some trusts make distributions to the beneficiary (or beneficiaries) over time. Others instruct the trustee to distribute just the trust's earnings or the amount the trustee thinks the beneficiary needs. Some trusts may require the accumulation of all income for distribution at a future time.

## What kinds of trusts are most commonly used for this type of planning?

There are many different types of trusts that serve different purposes. Laws that affect trusts also vary from state to state. However, most states offer some form of supplemental, discretionary or even cooperative master trust. These are the types of trusts usually recommended when parents want to protect their child's government benefits that the person needs. Some of these are referred to as "special needs trusts."

**Supplemental trusts** - Supplemental trusts are designed so the principal and its earnings supplement the beneficiary's care and does not replace the funds required to pay for this same care. This kind of trust is

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good for the SSI and Medicaid recipient whose assets cannot exceed specific levels. The trust grantor can carefully direct the trust not replace the cost of services covered by Medicaid. Instead, the trust would require the trustee to only provide funds for certain items, services or other expenses not covered by SSI and Medicaid. Supplemental trusts can also be set up for someone who is not on SSI and Medicaid.

**Discretionary trusts** - Some states allow the trust grantor to give the trustee full discretion in how much or how little of the trust to distribute. This kind of trust can also contain provisions that limit distributions so that the person remains eligible for government benefits. The trustee of a discretionary trust must be very careful not to distribute money from the trust for goods and services or outright to the beneficiary in a manner that will disqualify the beneficiary from receiving benefits. There are several drawbacks to a discretionary trust. The trustee must be very knowledgeable about the type of benefits a person is receiving and the related eligibility requirements. The trustee has total power over all distributions and may hold back all trust distributions to the detriment of the beneficiary.

## What is a "master cooperative trust?"

Sometimes referred to as a "pooled trust," these are special trusts that some organizations have created to serve families. Instead of setting up an individual trust account, these types of trusts allow families to pool their resources with other families. The pooled account is usually managed and invested as one large account. This reduces administrative fees as there is only one account and increases the total amount of principal for investments. Beneficiaries of these trusts usually receive earnings based on their share of the principal.

Master cooperative trusts are helpful to parents with smaller estates and parents who have difficulty finding an appropriate trustee. Many chapters of The Arc operate these trusts, so there is more assurance of an informed, sensitive trustee who knows about the care and support of individuals with mental retardation. Additionally, some master cooperative trusts will serve people with disabilities other than mental retardation. The Arc's *Future Planning Resources* noted at the end of this *Q&A* provides information on master cooperative trust programs throughout the country.

## How do I go about setting up a trust?

There are basically two ways to set up a legal trust. It can be testamentary or inter vivos (living).

**Testamentary** - This means the trust is part of a will and does not take effect until after the person who drew up the will dies. Parents can change the trust's terms any time the will is changed. So, if the intended beneficiary should die first, the will and trust can change. Tax-wise, this kind of trust does not require the person to file or pay income tax on it since there are no funds in it until after that person dies.

**Inter vivos (or Living)** - This means the person sets up a trust before dying. In doing so, the parents and/or others can make regular gifts to such a trust. Grandparents can make testamentary bequests from their will to the trust set up for the child with mental retardation. Parents can be the trustee and manage the trust according to their own discretion. They can also assign someone else to be trustee to see how that person would manage the trust.

Living trusts are either revocable or irrevocable. This means parents can change a revocable trust or end it before they die. With an irrevocable trust, parents set up the trust and give up most power to change or end it. Both ways of setting up trusts have different tax advantages and disadvantages according to the size of the parents' estate, family situation and many other factors. Remember, though, it is important that parents or others consult with an attorney about which kind of trust suits that particular family's financial and tax situation.

## Can I preserve my child's eligibility for SSI or Medicaid if my child has already received an inheritance?

Recent changes in the Federal Medicaid law allows an individual, in some cases, to transfer an inheritance to a certain type of supplemental trust and immediately qualify or re-qualify for Medicaid. These changes are included in the Omnibus Budget Reconciliation Act of 1993 (OBRA '93). OBRA '93 allows trust planning opportunities only to certain people who are disabled and to their aging parents who may need Medicaid services in the future. OBRA '93 allows a parent of a child with a disability or person with a disability to set aside funds in a supplemental needs trust. The trust must be carefully written to comply with OBRA '93 regulations and requires that the state providing services for the individual with a disability be paid back for the cost of services when the beneficiary dies. It is critical that the attorney drafting the trust is knowledgeable about the OBRA '93 legislation.

**Note:** This *Q&A* is only a general overview of one part of future planning. Families should work with a knowledgeable attorney or financial planner to explore other options of planning prior to making legally binding decisions. It is highly recommended that readers also review the materials in the *Future Planning Resources* list before and during planning.

To obtain a copy of The Arc's *Future Planning Resources*, a list of books, agencies and other resources that address financial and legal planning, send a request and $2 for postage and handling to:

The Arc of the United States
P.O. Box 1047
Arlington, Texas 76004

*Future Planning Resources* can also be found on The Arc's World Wide Web site at:
http://TheArc.org/welcome.html

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